Social and Economic Research Project Reports *No. 7*

A Multidisciplinary Study of Stigma in Relation to Hansen's Disease Among the Tausug in the Philippines

Final Report of a project supported by the TDR Social and Economic Research Component

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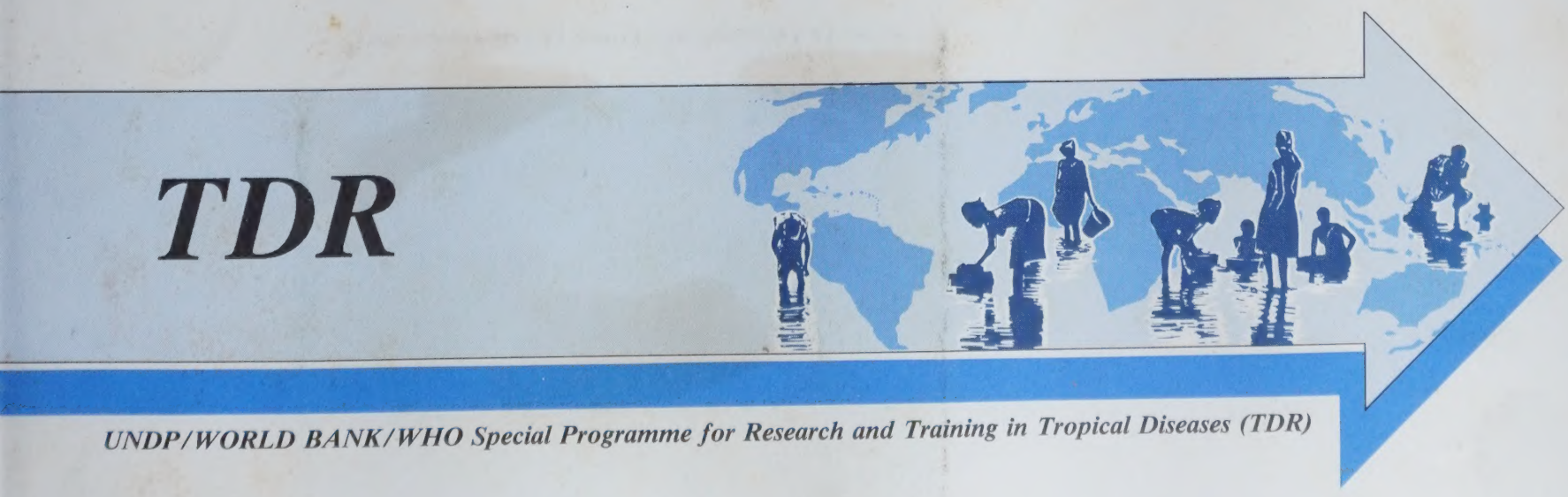

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TDR/SER/PRS/7

***SER Project Reports** appear as part of a series of unedited final reports resulting from projects supported by the UNDP/WORLD BANK/WHO Special Programme for Research and Training in Tropical Diseases (TDR). These reports are submitted to the TDR Steering Committee on Social and Economic Research for review and evaluation upon completion of a project. Project reports included in this series have not been published in their entirety elsewhere.*

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Foreword

The UNDP/WORLD BANK/WHO Special Programme for Research and Training in Tropical Diseases (TDR) is a globally coordinated effort to bring the resources of modern science to bear on the control of major tropical diseases. The Programme has two interdependent objectives:

- To develop new methods of preventing, diagnosing and treating selected tropical diseases, methods that would be applicable, acceptable and affordable by developing countries, require minimal skills or supervision and be readily integrated into the health services of these countries;

- To strengthen -- through training in biomedical and social sciences and through support to institutions -- the capability of developing countries to undertake the research required to develop these new disease control technologies.

Research is conducted on a global basis by multidisciplinary Scientific Working Groups on the six diseases selected for attack: malaria, schistosomiasis, filariasis (including onchocerciasis), the trypanosomiases (both African sleeping sickness and the American form, Chagas disease), the leishmaniases and leprosy. Scientific Working Groups are also active in the "trans-disease" areas of biological control of vectors, epidemiology, and social and economic research. The training and institution strengthening activities are limited to the tropical countries where the diseases are endemic.

The *Social and Economic Research Project Reports* series represents a new communication venture undertaken by TDR's Social and Economic Research (SER) Component. This series has been launched to facilitate and increase communication among social scientists and researchers in related disciplines carrying out research on social and economic aspects of tropical diseases and to disseminate social and economic research results to disease control personnel and government officials concerned with improving the effectiveness of tropical disease control.

Research reports published in this series are final reports of projects funded by TDR and usually include more material than ordinarily published in peer review journal articles. TDR considers this material to be valuable both for investigators involved in the study of social and economic aspects of tropical diseases and for professionals involved in training programmes in the social sciences, economics and public health. The series should acquaint those working on similar problems with approaches undertaken by others, in order to test new approaches in different settings, and should provide useful information to personnel in disease control programmes and related agencies.

All requests for further information should be addressed to: Dr C. Vlassoff, Secretary, Steering Committee on Social and Economic Research, TDR, World Health Organization, 1211 Geneva 27, Switzerland.

Tore Godal, Director

Special Programme for Research
and Training in Tropical Diseases
TDR

PREFACE

Since 1979 the Social and Economic Research (SER) component of the UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) has been supporting research aimed at improving the effectiveness of disease control programmes through the incorporation of social, cultural and economic factors into the design and implementation of control programme activities. In aiming towards this overall final objective, two intermediate objectives guide TDR's social and economic research activities:

- To determine the impact of social, cultural, demographic and economic conditions on disease transmission and control.

- To promote the design and use of cost-effective and acceptable disease control programmes and policies.

The study undertaken by Dr Paz and her team explores in greater depth some of the findings and hypotheses developed in earlier studies of stigma and problems of leprosy control in the Philippines. It investigates the linguistic aspects of Hansen's disease, and proposes to use the findings of the study for the development of educational material and training programmes for disease control programme staff. As such, it corresponds directly to the objectives of SER in representing action-oriented research towards the control of TDR's target diseases.

This project is an excellent example of the kind of multidisciplinary approach required for studies on the social and economic aspects of tropical diseases. The team consisted of a linguist, a psychologist and a historian, and, as the study shows, the researchers worked in close collaboration with health personnel. It is hoped that the results of this study will be translated into actions which can break through the barrier of stigma even in highly traditional populations such as the Tausug.

Carol Vlassoff, Secretary
Scientific Working Group and Steering Committee
on Social and Economic Research

Special Programme for Research
and Training in Tropical Diseases
TDR

ACKNOWLEDGEMENTS

I wish to acknowledge the financial and practical support received from the UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) which made this project possible and to thank it for its confidence in the Principal Investigator.

The successful completion of this project is the result of the efforts of many people. It is both a pleasure and privilege to acknowledge their contributions.

Dr Leslie Bauzon, Dean, College of Social Sciences and Philosophy; Research consultants - Dr Florentina Castillo, Head Administrator, Sulu Sanitarium, Dr Ernesto Constantino, Linguistics Dept., CSSP, UP, Professor Abraham Sakili, Chief Translator, Jolo, Sulu; Research staff - Ms Loudette Almazan, Mr Edmund Gumbakali, Mr Nick Fernandez; and Clerk Typists - Ms Flor Robles, Ms Evelyn Bolinas.

We also wish to acknowledge the assistance of the Medical Health Staff of the Sanitaria and Skin Clinics - Dr Nelia Amin, Provincial Health Office, Head of the Sulu General Hospital, Dr Gerardo Aquino, Head Administrator, Mindanao Sanitarium, Dr Milagros Fernandez, Deputy Regional Director, Dr Purita Fernandez, City Health Office of Zamboanga, Dr Hermelinda Pelino, Chief, Skin Clinic, Sulu Sanitarium, Ms. Estella Lorenzo, Chief Nurse, Ms Preciosa Cheong, Lorna Pestadera and Nympha Tan (Nurses Sulu Sanitarium Skin Clinic), Monalee Enriquez, Nurse, City Health Office, Skin Clinic, Zamboanga, Miss Teresita Burias, Social Worker, Sulu Sanitarium Skin Clinic and all the very cooperative informants who are too numerous to name.

Consuelo J. Paz
1 July 1990

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INTRODUCTION

The view that health problems are socio-cultural as well as medical has lead to the recognition of the role that the social sciences can play in disease control. This is particularly evident when the availability of modern drug therapy is not the main problem in arresting or eradicating a prevalent disease such as HD in the Philippines.

In the Philippines the mere mention of leprosy brings on shudders, nervous laughter, a call on the almighty for mercy or some other reaction indicating fear, squeamishness or a strong aversion to anything related to this unfamiliar sickness. Although Hansen's Disease (HD) is documented in the Philippines as early as the 17th century by the Spanish colonizers, little is known about this most dreaded disease. Some people believe HD is legendary while others believe it was eradicated some time ago. Only a small number of medical personnel trained specifically for its control are able to diagnose HD. This scant knowledge of HD has cloaked it in mystery, perpetuated a fear of it and has resulted in the strong stigmatization of hansenites.

Stigma refers to the complete or partial discontinuance of the relationships between the hansenite and the non-hansenites and the attendant social acts directed at the hansenite. Stigma/stigmatization results from a lack of knowledge of HD and at the same time is largely responsible for this lack of knowledge.

The assumption of this study is that the stigmatization of HD stands in some way against effectively controlling and treating the disease (1). Consequently this study sought answers to several related questions among the Tausug, an ethnolinguistic group in the Philippines (2). Why is stigma attached to HD? What are the manifestations and effects of stigma on the sick? What is the significance of stigma management in relation to disease control programmes? Does the medical staff contribute to the perpetuation of stigma, and, in what ways could the knowledge of stigma help in the improvement of disease control?

This study uses a multidisciplinary approach to examine the manifestations of stigma, it's effects on the sick and the community, and the coping mechanisms of the sick and their relatives among the Tausug. It is hoped that the knowledge gained can be used to prepare and disseminate culturally sensitive educational material for an effective HD control programme. To this end, the study concludes with some recommendations for improving the design and delivery of the HD control programme.

Related Studies

Studies exist on stigma in general (Goffman, 1968) and in relation to endemic diseases in particular (Bijleveld, 1978; Meisels-Navon, 1984; Pathan, 1984; Valencia, Ventura and Paz, 1984) but not in the Philippines. In "Stigma", Irving Goffman groups the attributes which give rise to stigma into abominations of the body, blemishes in individual character, and those as a consequence of class, race, nationality and religion. Iman Bijleveld in "Leprosy in the three Wangas, Kenya: Stigma and Stigma Management" states that stigma has two essential components: it must have moral implications and must arise from standardized thinking and behavior.

There are a few other studies on stigma and HD. Zachary Gussov and George Tracy published a study in 1968 entitled "Status Ideology and Adaptation to Stigmatized Illness: A Study of Leprosy". Liora Meissels-Navon's paper "Hansen Patients in a Milieu of Symbolic 'lepers': on Ignorance, Prejudice and Self Prejudice" presented at the 12th International Leprosy Congress in New Delhi, India (1984) discusses how stigma management by secrecy is practiced in Israel. B.R. Pathan's paper "Stigma in Leprosy" presented at the same congress, examines how stigma is experienced by those afflicted and by those unafflicted and the patterns of behavior that emerged based on their reactions to the disease in the rural areas of Poona, Maharashtra, India.

The Valencia, Ventura and Paz study "A Study of the Knowledge, Beliefs, Attitudes and Practices of Ilocanos on Leprosy" (1984) although not specifically on stigmatization, suggested the significance of stigma and self-stigma in an individual's decision to seek treatment.

The significance of stigmatization was also evident in a related study. In "Managing Triadic Interaction Basic for Organizational Assessment (OA): A Guide for Leprosy Control" (1986), Valencia, Ventura and Paz studied the impact of the interpersonal behavior of the medical personnel, the patients and the community, and the effects of the community participation schemes of the existing control programme. Stigmatization seemed to play a significant role in the interaction between the patients and the medical personnel. From a review of these studies, it became evident that research on stigmatization was basic to the treatment and control of the disease.

Objectives and Research Design

The specific objectives of the study were:

1. To describe and analyze stigmatization and stigma management in relation to leprosy as manifested by the Tausug.

2. To arrive at a body of knowledge which could be used in the educational material and medical staff training of the disease control programme of the Tausug and be potential input into the national control programme.

To meet these objectives a mulitdisciplinary approach which included historical investigation, a psycholinguistic analysis of taped oral data, and psychological testing and analysis was developed.

Language is an effective source of information because factual information can be gathered from it. But often the covert messages, thoughts, emotions and perceptions which are expressed by the speakers' unconscious use of certain lexical and syntactic forms can be more revealing. An analysis of these linguistic forms reveals the more sensitive views of the informants. The results are often more informative than what can be obtained from observation or from structured interviews for statistical or quantitative analysis.

For this study information was gathered through unstructured interviews with hansenites, relatives, medical personnel, other members of the community, folktales and historical

documentation about HD. The interviews were conducted in Tausug by the principal researcher and research assistants. To ensure uniformity and thoroughness a list of guide topics (Appendix A) were used for the interviews. The interviewers attempted to elicit information indirectly by inquiring about daily activities, friends, likes and dislikes, desires, fears and aspirations. Direct questions or questionnaires were not used as Filipinos in general do not respond favorably to these.

Interviews were conducted individually, especially with hansenites, or in groups of two or more. Group interviews encouraged spontaneous responses and discussions from which group opinion or norms were revealed. Group discussions also allowed the simultaneous checking of information. In most communities groups gathered around the neighborhood store, in the town plaza or by a wayside refreshment stall. All interviews were recorded.

In addition to the interviews, unobtrusive observations were made of the relations existing between the hansenites and the family, medical personnel, and the rest of the community. Data from folktales and historical documents were obtained from the community and from neighboring islands and ethnolinguistic groups (3).

The information gathered from interviews, folktales, and historical documents were translated into Filipino and English. Efforts were made to keep as close as possible to the original sense expressed in Tausug (4). At times, the awkward English translation of the excerpts included in this paper as illustrations are due to the failure of these efforts. The excerpts were chosen because they best illustrate the topic being discussed.

The manifestations of stigmatization are expressed either overtly or covertly. Both external stigmatization and internal stigmatization (self-stigma) are expressed overtly. Some manifestations however such as fear, squeamishness, revulsion or disgust may be expressed covertly. The stigmatizer may unconsciously manifest stigma and at the same time deny his feelings, not consciously knowing that he expressed such feelings. This type of stigmatization is not observed but is revealed in the language of the stigmatizer.

An analysis was made of language structure such as sentence phrases and lexical forms, which expressed perceptions of HD and reactions to the disease in terms of stigma, self-stigma and coping. The informant's choice of structures conveyed overt messages and revealed the covert perceptions and emotional state they were in. The different terms used to indicate the disease were analyzed for different types of reactions. The competing terms, archaic forms and innovations used by the informants indicated the change in the intensity of stigma and the coping mechanisms used.

Other linguistic structures such as types of sentences, particles and affixes showed the mood and motives for stigmatization. These structures revealed reactions which were covertly manifested in them. Information on the knowledge, attitudes, beliefs and practices relevant to HD were also obtained from the linguistic analysis.

A life events approach, similar to that utilized by Holmes and Rahe (1967) in their study on stressful life events, was used in the psychological component of the study. On the premise that stigma associated with HD results from learning an attitude, the psychological study followed a

model which implies that the interpretive aspects of diagnosis from the patient's viewpoint is relevant to understanding his attempts at coping with the disease. The model also implies that the relationship between stigmatization and the socio-cultural and medical milieu is a two way process. The life events approach was used to identify stressful events which revealed manifestations of stigma and the patient's psychological and social adjustment in coping with the disease.

A check list of life events (Appendix B) was presented to the informants. They were asked to give the estimated value of each life event using a scale from 1 to 100. No reference point was used as it was necessary to discover the values for the particular group of respondents. The items were presented at random to allow each respondent to control for the effects of the order of the presentation.

Historical documents were also examined to provide a perspective of HD and its spread in the country. Accounts of its spread and the establishment and progress of the control programme at the national level and in the Tausug community were discovered. Both primary and secondary sources were utilized in reconstructing the historical account of HD and stigmatization. The documentary evidence of stigmatization helped to shed some light on the change in the manifestations and intensity of stigma. These historical facts were verified by the etymological information found in dictionaries and by comparative linguistic evidence.

The history of HD in the country and specifically in the Mindanao-Sulu area was reconstructed by Isagani R. Medina, Professor of History, University of the Philippines. The psycholinguistic analysis of the oral data was accomplished by Consuelo J. Paz, Professor of Linguistics, University of the Philippines. The psychological testing and analysis was conducted by Elizabeth R. Ventura, Professor of Psychology, University of the Philippines. This paper focuses primarily on the psycholinguistic component of the study. A complete report on the psychological component of this study is contained in E. Ventura's paper entitled "Report of the Psychological Aspects on WHO Project No. 2" and I. Medina's full investigation of the historical study of HD is contained in a separate paper entitled "HD in the Philippines 1578-1987".

Site Selection

The selection of the Tausug for this study was based on three factors: HD prevalence rate, linguistic reasons, and the scarcity of studies on HD among this group.

Historical documents show that the Mindanao Treatment Station, a skin dispensary, was established in Zamboanga, Sulu Province, in 1930. As reported in the Memorandum for Treatment Stations and Dispensaries (May, 1931) two treatment substations, Lanao and Cotabato, had been organized. This suggests that HD has been a significant and persistent health problem in the area. The language, customs and beliefs of the people in the regions provide cultural evidence that a considerable period of time of HD prevalence must have elapsed to allow the development of such adverse and entrenched attitudes towards HD.

Table 1 indicates that of the provinces with prevalence rate records for HD, Sulu shows the highest rate of 3.89 per 1,000. In March 1985, there were a total of 2,061 registered out-patient cases in Sulu, 1225 active and 836 "floating" cases. Ilocos Sur which is populated by the Ilocano,

one of the largest ethnolinguistic groups in the country, shows the next highest rate. The Ilocano also populate Ilocos Norte, la Union and Abra provinces which are also rated among the ten highest prevalence rates. Despite the fact that the Ilocanos (cf. Valencia, Ventura and Paz, 1984, 1986) are a larger and more widespread group it was decided that it would be beneficial to study a group that had not been studied for HD.

Table 1

The Top Ten Provinces in the Philippines with the Highest HD Prevalence Rates, 1985*

Provinces	Prevalence Rate/1,000 pop.
Sulu	3.89
Ilocos Sur	3.74
Batanes	2.80
Ilocos Norte	2.55
Palawan	1.77
Metro Manila	1.61
La Union	1.37
Abra	1.20
Rizal	1.11
Cebu	1.08

* From the Annual Report of the Leprosy Control Service, Ministry of Health.

The Tausug of Sulu speak a language distinct from over a hundred other languages spoken in the Philippines. Although Tausug is a lingua franca in its region, it is a smaller linguistic region which consists mostly of an archipelago. This language still reflects the group's indigenous customs and beliefs since, largely because of geographical reasons, the region has not been that exposed to other languages. The Tausug are a large enough group to be representative of the Sulu-Mindanao area.

The Tausug are found mainly on one of the seven island groups of the Sulu Archipelago located in the Southwestern most area of the country. They are the largest ethnic group in the Sulu province.

The land area of Sulu is 2,688 square kilometers with a total population of 425,617 and a high density of 168 per square kilometer. The Sulu is one of the most productive fishing grounds of the country and is well known as a "fruit basket" of the country. The population is highly mobile and most travel is done by sea.

This province has one of the lowest literacy rates in the country. More than other groups in the country they have maintained their indigenous ways. They are known for their warlike nature and fierce resistance to control from foreign conquerors and even the national government.

The selected study sites were Jolo, Danag, and Zamboanga. Jolo is a rural town on one of the biggest islands of the Sulu archipelago. Aside from commerce and trading, most of the population is engaged in fishing and agriculture. Although the commercial center of Sulu, Jolo has few modern buildings and well kept streets. This is partly due to the political unrest in the region. The town was razed to the ground in 1975 and hundreds were killed or rendered homeless when government troops attempted to flush out members of the Moro Nationalist Liberation Front (MNLF). This group was protesting martial rule and oppression of the Marcos' government.

The population of Jolo is mostly Tausug with a mixture of Samal, another linguistic group, and Christian immigrants. The Tausug are highly religious people who follow closely the traditions of Islam. The majority of the Tausug live in villages of indigenous bamboo houses built on stilts over the sea and connected to each other by an intricate network of bamboo catwalks. The informants from this area make up the "rural low" category of the sample.

The Sulu General Hospital and the Sulu Sanitarium are located in Jolo. The skin clinic which cares for hansenite out-patients and which has jurisdiction over all the Sulu islands is located in the sanitarium. The sanitarium is located near the hospital in a well-kept compound with vegetable gardens tended to by hansenite patients. Just outside the sanitarium lives a community of hansenites who were once patients of the facility or who were not able to obtain accommodation in the institution and preferred to take up residence in this community rather than return to their homes.

Danag is a prosperous agricultural village located in the hills outside of Jolo town. It is well known for its coffee and agricultural products. The village consists of typical Tausug houses of bamboo and grass thatched roofs. These houses have a spacious living area which serves as a living room during the day and as a bedroom at night. A wide porch runs the width of the house which is raised five feet from the ground. The bamboo slatted floors and woven bamboo walls keep the house cool and airy. A bridge-like floor also of slatted bamboo is connected to the main structure and extends into a covered area which serves as the kitchen, bath and wash area. The size of the house depends on the size of the extended family. The indigenous attire is still worn by a good number of the population, especially the women. The informants of the "rural high economic status" category of the sample were from this area.

Zamboanga, known as a genteel Southern city, has a highly heterogeneous population which includes Zamboangenos, Tausugs, Samals, Cebuanos, Tagalogs, Chinese and Filipinos from other ethnic origins. Urban, picturesque and with a busy commercial center offering goods from neighboring Borneo and Indonesia, Zamboanga attracts many tourists.

The provincial hospital is located in the city while the sanitarium is located just outside of it. The Mindanao Central Sanitarium is located in Pasobolong and consists of several well kept, low-rise buildings covering a large compound. A community of hansenites who were formerly hospitalized in the sanitarium live within this compound. They are either out-patients or those who simply wish to live there. In Zamboanga city itself there are two places where a concentration of Tausugs and hansenites are found; Riohondo and Calinan.

Calinan is by the seashore where the sanitarium was previously located. A small community of hansenites and their families remained there when the sanitarium was moved. They make a living by fishing and cultivating, harvesting and selling sea weed. The sample for the psychological testing was from this fishing village and from the community of hansenites living within the Mindanao Central Sanitarium. Informants for the "urban high" and "urban low" categories were from the Zamboanga area.

Sample

The sample was drawn from two types of locations: an urban/semi-urban town (U) and a rural village/barrio (R). The sample consisted of five groups: the sick (S), kin/relatives of the sick (K), associates/friends of the sick (A), health/medical staff (H) and individuals who knew no one with HD (X). Each group had an equal amount of male and female informants.

The sample was categorized into high (h) and low (l) according to economic status. These categories were based on the house or households which the informants occupied (Household Survey). Within this category educational attainment was considered when feasible.

The sick (or S) informants were identified through the clinical records of the skin clinics or travelling skin clinics and the cases reported to the Ministry of Health. Individuals who were identified by members of the community as hansenites, whether or not this was true, were considered as S informants since they were subject to stigmatization or were suffering from self-stigma.

An additional ten informants, two for each group, were interviewed for feedback on the tentative research findings.

Table 2

Summary of the Sample

Groups	Urban high	Urban low	Rural high	Rural low	Sub-Total	Total
Sick (S)						
male	4	4	4	4	16	
female	4	4	4	4	16	32
Kin (K)						
male	3	3	3	3	12	
female	3	3	3	3	12	24
Associate (A)						
male	3	3	3	3	12	
female	3	3	3	3	12	24
Know no one with HD (X)						
male	2	2	2	2	8	
female	2	2	2	2	8	16
Health Staff (H)						
male					5	
female					5	10
Feedback informants						10
Total						116

In addition to the sample above a supplementary sample of twenty-four hansenites was included for psychological testing. Nine were female and fifteen were male. The females ranged from 17 to 51 years of age while the males ranged from 18 to 45. Consequently the total sample size for the study was 140 informants.

Although limited by budgetary constraints, the sample size of 140 informants was found to be sufficient for the volume and quality of data required. The information gathered from the sample was massive and included 150 cassette tapes (C90), written interviews, tests, and historical and contemporary documents.

In Zamboanga the City Health Office, which manages the skin clinic, and the Mindanao Central Sanitarium were most helpful in locating patients and their families for this research. In Jolo the Sulu Sanitarium which services all 13 districts of Sulu and the Sulu General Hospital provided much assistance and served as the institutional bases for the research.

STIGMATIZATION BY THE TAUSUG

You will recall that earlier in the paper stigma was described as the complete or partial discontinuance of the relationships between the hansenite and the non-hansenites and the attendant social acts directed at the hansenite. To understand stigmatization by the Tausug it is first necessary to comprehend their perceptions of HD, its causes, and the transmission of the disease. This knowledge is required before we can understand causes of stigma, the manifestations and the effects of stigma, and the strategies used for coping with the disease.

When symptoms identified by the group to be those of HD were observed in an individual, whether or not the symptoms were those of HD, stigmatization became operational. It was the perceptions and beliefs of the individual or the community rather than the medical diagnosis which triggered stigma. These perceptions, along with traditions and norms, form the attitude of the group towards HD and hansenites.

Figure 1

Ideology of Stigma Diagram

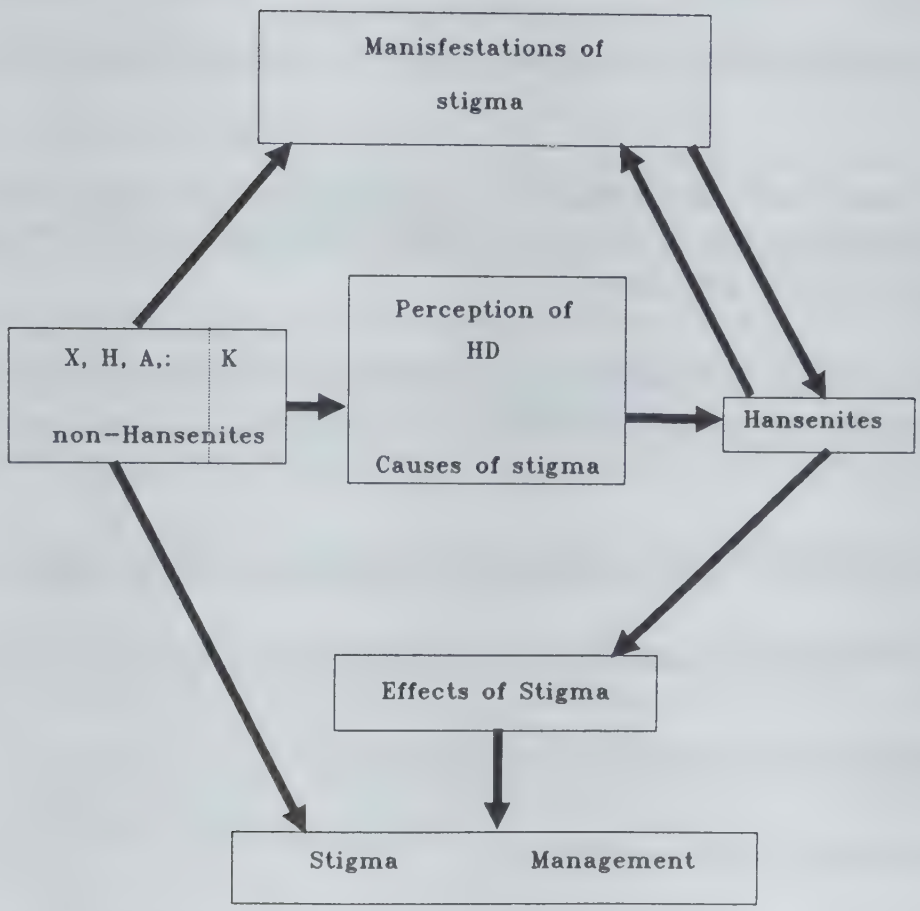

Figure 1 illustrates stigma manifested by non-hansenites and hansenites. Hansenites manifest a stigma directed towards themselves, hence the double arrows directed to and away from the hansenites.

The effects of stigmatization on the hansenite reflect the manner in which they coped with stigmatization. In some ways the close relatives of hansenites found themselves in situations where they too had to cope with stigma. This is illustrated in Figure 1 by the broken line that separates kin (K) from the rest of the non-hansenites in order to indicate their stigma management.

The Language of the Tausug

Since all thought, sentiments and aspirations are expressed in language, it can be said that language is the most credible source of information. Certain linguistic structures emphasize, clarify and complete the message sent by a speaker. These structures allow and are often responsible for the successful reception of the message by the listener.

In the Tausug language, stigmatization can be better understood by the following syntactic structures.

1. Particles. These linguistic forms reveal the mood of the speaker and give added meaning to the emotion expressed by the speaker.

> I just only stay outside because I now cannot go to our house, (they) just come to see me already...

"Only" and "already, now" were used repeatedly to emphasize the change in the relationship between the hansenite and the rest of his family. Other particles used were "really", "just", "like, as if, it seems", "maybe, might", and "also".

2. Fixed/set phrases. These consisted of expressions and exclamations that revealed strong reactions. These were often introductory phrases that were used to show the speaker's position on the matter.

> If you ask me/As far as I know, it seems not...Let it go away! God forbid. God's will.

3. Sentence types. Different sentence types were used to enhance the message.

a. questions. These indicate uncertainty or hopelessness.

> What do they call me? I don't hear them.

b. negative sentences. These show a negative viewpoint.

> I don't attend, I'm dirty. I don't know anything about that sickness.

c. short sentences. These indicate shyness, doubt or resentment.

I don't know.

d. discontinued sentences. These show uncertainty in how the speaker wants to express himself or a desire to change his mind about wanting to say something.

I'm ashamed already to show myself because it's like ... They mock us, just because we're...

4. Affixation. The choice of affixes indicate the attitude of the speaker towards the topic being discussed. Verbal affixes best illustrate this because they indicate the focus of the sentence as well as the aspect of the action. A speaker selected the goal focus affix for example when he wished to highlight the object to which the action of the verb was directed. He selected the continuing aspectual form when he wished to indicate the ongoing state of the action.

His sickness rots, (his) hand curled up/shrunk.

In this example, "sickness" and "hand" were focused by verbal affixes.

5. Substitutes and fillers. Substitutes such as pronouns and acronyms were used in place of terms for HD, hansenites or a symptom of HD to avoid using the actual term. This was usually a result of fear or stigma. Fillers were used when a speaker hesitated or wished to avoid saying something.

God forbid I become like that.

That's why people are careful of that thing.

In these examples the words "that" and "that thing" substituted for HD. At times the fillers took verbal affixes or were verbalized: to so this thing/ to whatchamacal it.

You would think one would not do what's this, would not go near people.

... because people would what's this, they also (would do) like that.

6. Quotes. Speakers resorted to quoting people of authority or elders to give credence to what they were saying. At times this was done by implying that what they were saying was common knowledge. This was usually in the form of direct or indirect quotes or sentences which contained "they/he, she said/say". This strategy communicated the caution felt by the speaker in revealing the information in the message.

Eh, from what I hear, they say that it is leprosy.

It is said that their ancestors were cursed.

When I went to the well the people whispered, "Don't what this, that sickness is contagious".

7. Repetition. Words, sentences or phrases were repeated for emphasis, to signal a covert message or when hesitating to say something.

"What's that?" they asked. Eh, I said, "I don't know". And yet I'm already using the tablets. I simply answered, "I don't know."

8. Metaphor. This strategy of using metaphors was used when the speaker sought clarity when describing something or when he was deeply bothered by the topic. In describing the reaction of the people he met on the street, an informant said:

...like they flew as if with wings.

Some informants described HD as "octopus like". A hansenite vividly described his symptoms using metaphors which alluded to objects in his environment.

It was round like a seashell. A kind of shell. Here on my foot. Then it was gone. It came out on my ears. My ears became big already, like a sail.

9. Lexicon. Choosing words either consciously or unconsciously is constantly practiced in communication. When the topic is an emotional one, this is even more the case. The data showed how the precise vocabulary of a speaker made the message clearer or verified a hypothesis.

Nobody (would) want (HD) to descend on (himself).

The use of "descend/alight on" expresses the concept of contamination or infection.

10. Direct responses. Responses which did not answer a question indicated a studied avoidance of the topic being discussed. For example when a hansenite was asked how his disease interfered with continuing relationships with his friends, he suddenly said that death would solve all his problems.

Of course we are all afraid of those who have that sickness. But up to the present, nothing has happened. If I were afraid of contamination, I would not have taken on the responsibility of one who is sick.

The Tausug term translated as responsibility actually means "to carry on one's back". This revealed how the relative, in this case the wife, felt about caring for her hansenite husband. She expressed a feeling that she was duty bound, a responsibility she felt she had to meet.

Another wife expressed her faith in medicine. This faith helped dispel her fear.

Medicine, there's medicine to cure it.

Note the repetition of "medicine" which emphasized her hope in its effectiveness.

To emphasize the fact that she did not fear infection, another wife said:

> We live together. We have only one bed (only one set of bedding).

A significant economic factor related to the fear of HD was revealed in the data. The fear of losing the ability to earn a living was often anticipated and perceived as an unavoidable consequence of having the disease. For this reason many hansenites stopped working upon learning of their sickness. It is noteworthy that the psychological test on important negative life events indicated that Tausug women were stressed more by economic instability than the men.

There is a strong fear of ostracism among the Tausug. They are a highly clannish people who put much weight on interpersonal social ties and activities such as belonging to a peer group and attending daily service at the mosque.

> We can no longer go together, because the truth is we are truly very close friends. I am now ashamed to go with him, likewise he too with me.

The following account supplied by a neighbor of a hansenite portrays the point of view of the non-sick.

> His sickness rotted/shrunk/curled up his hands like that. Because of this shrinking of his, he could no longer eat. Death overcame him as he just lay there. He was burned (cremated) in order to kill the germs. If he was not burned, his children and grandchildren would have been contaminated/infected. Then the house where he stayed was burned.

It is easy to understand how fear nurtures stigma when the perceptions of the disease as crippling and deforming and perceived consequences attendant to it are examined.

Squeamishness/Revulsion

Squeamishness towards the disease was quite common. This was due to the physical symptoms such as rashes, watery pustules, bumps and the more serious deformities, exhibited by the hansenites. This reaction was different from the fear of physical deformities discussed above. Squeamishness or revulsion was an immediate reaction on contact or to direct experience with HD or hansenites. Fear of physical deformity was not the result of any direct experience but was brought on simply by the knowledge that it could happen.

The next two examples illustrate stigmatization brought on by squeamishness or revulsion. The use of "that thing" of "what/ how do you call it" as a substitute for the term for HD, or as a filler to bide time while thinking what to say next, communicates the uneasiness brought on by this fear.

> There was something already, I think it's been cured. This woman, its like I, what's this, her hands had this, one of them. The woman, it's like she had this. I then, but I think it's been like this, it was cured. I this, the person got cured. I really don't know, maybe I did not really look at it, she seems normal now.

An informant expressed his revulsion at the idea of touching or shaking the hand of a hansenite in this manner:

> I might shake hands but that is my feeling about it, I might shake hands ... I might shake hands but even if he were a friend with that, that is only his hand ... that is a little bit (part of his hand). You see it would (have to) be a friend, but it wouldn't be like from my heart (sincerely) that is wholeheartedly.

The repeated phrases, use of fillers "that, thing" and his decision to shake hands if the hansenite were a friend, but qualifying that he would only hold a portion of the hand and would not do it with sincerity, aptly communicated his squeamishness or revulsion towards the hansenite.

Customs and Beliefs

Certain customs and folk beliefs were partly responsible for the attitude of the Tausug towards HD. The belief that the disease was highly contagious and feared was probably the basis for the folk belief that HD originated in the "Northern part of Jolo" ie. some distant place. The belief that the disease was the result of a curse or a punishment from the Almighty was often expressed by the informants especially by the hansenites and their kin. The rituals used by folk healers to "cure" HD were dreadful enough to cause stigma and manifested the severe treatment hansenites expected from the community. Many of the rituals amounted to virtual punishment for what some hansenites perceived to be a situation beyond their control.

As part of their notion of contamination and transmission of HD, the Tausug believed it was necessary for the corpses and belongings of hansenites to be burned.

Folk or indigenous cures were used extensively by the Tausug and were usually the first type of treatment sought for most ailments. It was only when the condition of the patient seemed hopeless that medical help was sought at the skin clinic or sanitarium. The strong faith in indigenous medicine and the failure of these cures, was partly responsible for the perception that HD is incurable.

Perceptions of HD

The analysis of language and linguistic structures revealed the Tausug's perceptions of HD, its causes, and its transmission. These perceptions are important in order to understand the reasons behind the stigmatization of HD.

The Tausug perceived the disease as a dirty sickness.

> Eh, (one) becomes dirty with that sickness. Eh, even if (one) gets well, it will not be the end of it.

Wistfully, a hansenite expressed himself in this manner:

> I really/truly want my body to become clean.

HD was consistently described as a Tausug word meaning to corrode, disintegrate, eaten into, gnawed or wear away gradually. This word aptly depicts the perception, and strongly connotes, that the disease inevitably leads to frightening deformities.

Most of the informants were not able to give useful information about HD, especially those that did not know anyone with the disease (the X group). Often they were not sure which disease was being referred to. The interviewers avoided naming or identifying the disease allowing the informants to discern which it was without much prodding. But whenever the Tausug word meaning to corrode, or any of its affixed forms were mentioned, the informants immediately associated these words with HD even if they had had no personal knowledge or contact with hansenites.

HD was often identified as "melting/disintegrating sickness". The verb form in this case designates a progressive aspect.

> causes our flesh to disintegrate.

> ... so long as it causes melting/disintegrating like that (of) the hands, feet, they say it is leprosy.

This perception had economic implications which contributed to the attitude which nurtured stigmatization. Most informants expressed anxiety over the disabling effect of HD which they believed incapacitated them and prevented them from earning a living.

The Tausug perceived that HD was caused by either natural or supernatural causes. The natural causes included things taken internally such as chicken, salt or salty water. One common belief on causation is the concept of ***kagaw***. The concept of infection is related to this belief.

The Tausug believe that HD is caused by a germ. Although they do not conceive of the germ as a microbe, they believe that the ***kagaw***, a minute insect-like organism enters the blood stream and causes the ill-effects of HD, especially what they perceive of as the rotting of flesh. A similar concept was found among the Subanon, an ethnoliguistic group located in an adjacent area southwest of Zamboanga. According to the Subanon the germ is of different colors causing different types of HD and exists in a certain variety of bamboo.

The Tausug believe that HD is highly transmittable because the ***kagaw*** can crawl easily from one host to another. Conversing or shaking hands with a hansenite, buying at the same store, bathing in the same place, or just being near a hansenite exposes one to the ***kagaw*** and HD.

This belief persists even among educated Tausugs who have knowledge of modern health concepts.

> Eh, his germs will crawl to you. Eh, that will cause your destruction.

The Tausug also believed HD had a life of its own. In describing their symptoms, a number of informants referred to their sickness as a living organism, as in the following example.

> (It) disappeared, the moving thing died. When I grew older, it moved/lived (again).

The data show that poor health habits were perceived as one of the reasons the disease spread. More prevalent was the belief that chickens were instrumental in the transmission of HD. The informants reasoned that since chickens were allowed to roam around freely they could eat anything including human feces. In all probability chickens picked up the ***kagaw*** which could then be transmitted to humans through chickens and eggs.

Infection was considered more virulent for those with open wounds. The belief that HD was the result of neglected skin ruptures revealed the perception that the disease was progressive and even terminal. A number of informants felt that HD started as a wound and then spread to the rest of the body.

> It started as a wound on the foot ... then it climbed to my face.

Without mentioning the cause of his sickness, an informant described the concept of infection and transmission through prolonged contact.

> This (thing) of mine, my father was sick with leprosy. He contaminated/infected me ... I was still small, eh, we ... eat, sleep, do things together, live in one house with my father, all of us a family, one family; we stayed together.

Many informants believed that HD was caused and transmitted genetically, or as they say, through the blood.

> Could be from the blood because my mother has (it).

> The defect is in the blood.

> If you have the same blood, (you will get) that sickness. If you do not have the same blood, even if you embrace night and day, nothing will happen.

Having weak blood, which actually means being weak or not healthy, made one susceptible to the disease.

> When our blood is sick then we easily get sick.

Besides the natural causes of HD, supernatural causes such as fate, spirits or curses were revealed in the data.

Eh, I was probably destined by the Master.

I think it was planned by Almighty God that I would get sick like this.

I don't know. Those who have that sickness, they say it is hard to say. They say ahh, devils curse.

Notice how this last informant started with a curt denial, then went on by using the strategy of quoting others. This was done twice, to disassociate himself from the topic being discussed. He then hesitated with the filler "ahh" before he could mention what had apparently caused this reaction.

THE CAUSES OF STIGMA

The data showed that the causes of stigmatization among the Tausug were fear, squeamishness, customs, folk beliefs, and lack of knowledge.

Fear

The fear of the disease was expressed in strong terms. It was considered by some to be only second to death. The mere mention of HD brought on responses such as:

> I don't know anything (about it) and I'm afraid (of it).
>
> God forbid, no, let it go away.
>
> God forbid! Even if they were related, I would not let them live with me.

This last statement is a strong one considering that households usually consist of extended families. Notice that the statements were prefaced with a call on the Almighty and were short and terse; this emphasizes the fear experienced by the informants.

The fear of HD was based on the fear of contagion, fear of physical deformity, fear of the loss of the ability to earn a living, and fear of ostracism. Due mainly to the concept of the ***kagaw*** which was believed to be highly mobile, a strong fear of contagion was noted in two groups of informants: the associates of the sick (A) and those who knew no one with HD (X). The two other groups, the hansenites (S) and their kin (K), did not express the same fear. Hansenites no longer had this fear, and their kin expressed a fatalism rooted in their religion and acceptance of God's will.

The perception that HD is dirty or causes one to be considered dirty adds to this fear. The following excerpts show the fear of contagion of what is perceived of as a dangerous and incurable disease.

> I'm afraid of him because (of) that, I know (it) is dangerous. It's really very contagious because my mother said it takes a long time to cure that sickness. It doesn't get cured (even if you cure it) it (stays) in the blood and in the veins/nerves. What are called ***kagaw*** eat (drink) human blood. Even you put them in boiling water they don't die.

Notice the use of "that sickness" and the particles which were used for emphasis, "like" and "really".

Another fear, the fear of physical deformity, was intensified by the belief that the deformity caused by HD was inevitable, irreversible, and permanent.

> People are afraid of it. It never heals. It's watery.

The short sentences showed that the speaker was bothered by what he had to say. The general statement that the people were afraid of it without saying he himself was afraid, showed that the speaker wanted to be impersonal and wanted to distance himself. Describing a symptom as "watery", implied skin eruptions which indicated the perception that the disease was revolting.

> God forbid, that which she has already with her, at first her hand became swollen and red.

In this excerpt, fear was expressed initially by a call on God, then by avoiding the name of the disease by means of an indirect expression "that which she already has with her".

In some cases, the informants preferred death to HD which would inevitably lead to physical deformity.

> It would only cause the hands to wear down/disintegrate.

> (I saw it) in his hands, let it stay there in him, it is but correct to be called crooked.

In the latter statement fear was expressed as an aside, a wish that the sickness stays where it is and is not transferred to the speaker. It was also expressed by the image brought to mind by "crooked".

The attitude described above of the associates of the hansenites and those who do not know a hansenite were not shared by the hansenites and their kin. The hansenites through personal experience had learnt to live with their predicament. Their relatives, especially the immediate family, were resigned to a situation they could not avoid. There were some relatives who distanced themselves from or abandoned their hansenite relative, but this was out of exasperation and the desire for a better life, not fear.

Customs and Folk Beliefs

> When they got to know about him, he was told to ask for help (consult) the elders of the community. He consulted a herb/faith healer but he was not cured, he became deformed.

Indigenous healers were often consulted and rituals and offerings to the spirits were often made. One ritual cure practiced by the Tausug is based on the concept of the ***kagaw***. This organism was believed to feast on fresh blood. A cow was slaughtered and its entrails removed. The patient then crawled into the slit abdomen. It was believed that attracted by the fresh blood the ***kagaw*** would leave the patient and transfer itself to the slaughtered cow. After a short while the patient was taken out of the abdomen and the cow along with the ***kagaw***, presumably, was burned.

> A man sick with leprosy should kill a cow. My father was a healer. He would slaughter a cow. Put the one sick with leprosy inside the cow, afterwards when he gets out the cow is burned so that the ***kagaw*** was left inside. My father healed two women sick with leprosy (in this way).

A slightly less gory version was related by another informant.

> They say if the cow's neck is slit, the blood is fresh, you can really see what they call ***kagaw***. Yes, that is, they say they climb up to the blood. One way is to kill and skin (the cow) then let the person who has it hold (the flesh), then you'll know (see results).

Another ritual called ***kaja*** was an offering of chickens, coconuts and gantas of rice, eleven of each, and a sum of money. The offering included prayers and was performed on top of a mountain.

Lack of Knowledge

The most prevailing reason for stigmatization was ignorance or lack of knowledge of the disease. All the other causes of stigma, except to a lesser degree squeamishness, can be traced to ignorance of cause, transmission or cure of HD. The hansenites and their kin did not exhibit this as much as the other two groups. The following excerpts show ignorance as a clear cause of stigma.

> I don't know (about it), and that (thing) is frightening.

> As far as I'm concerned I call it cursed/condemned.

The nurse of the skin clinic in Zamboanga revealed that her husband was very much afraid that she might bring the sickness to their home. She solved this problem by reminding him that God might punish him for feeling that way and curse him with HD for being uncharitable. This demonstrates how ignorance was "corrected" by more ignorance.

Even among the highly educated fear of contagion prevailed because of lack of knowledge, thus contributing to the persistence of stigma.

> Even if he is a professional too, I won't go near him (a hansenite), I won't make friends with him also, for fear I would be infected.

This informant made use of the negative to emphasize his rejection of hansenites. This he did without knowing how the disease could be transmitted.

MANIFESTATIONS OF STIGMA

The stigmatization of HD by the Tausug was manifested behaviorally and psychologically. The behavioral manifestations were ostracizing or isolating acts which were observed in the communities under study. The psychological or mental manifestations were gleaned from the language data and from the results of the psychological testing.

The Tausug maintain strong clannish ties. This was found to be a consideration in an individual's relationship with friends or relatives who were hansenites. The strength of stigmatization was relative to this consideration. In general, the closer the relationship, the weaker the stigmatization was manifested, at least overtly. Often, continued association with hansenites was done grudgingly or conditionally by relatives or friends.

Figure 2

Intensity of Stigma

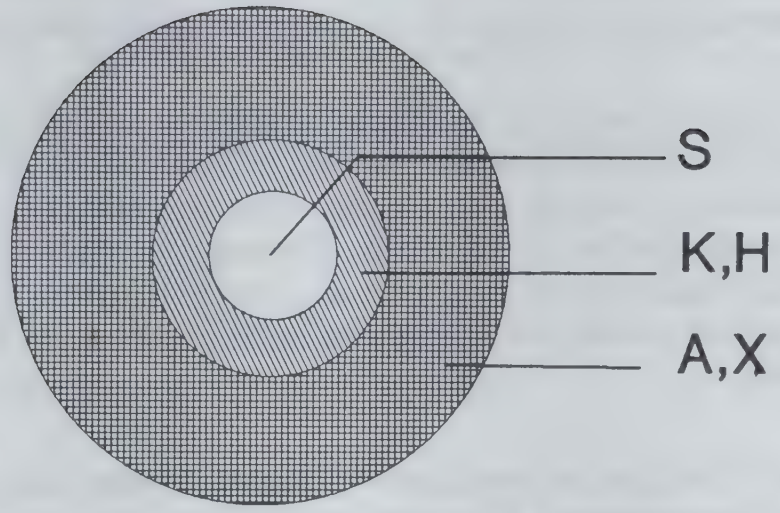

Figure 2 illustrates the intensity of stigmatization relative to the social and interpersonal relations of the stigmatizer and the stigmatized. The darkest shaded area represents the A (associates) and X (those who do not know a hansenite) members of the community. The lighter shaded section represents the K (kin of hansenites) and the H (health staff) members, and the lightest shaded area represents the S (hansenites). Self-stigma (cf. section on self-stigma below) accounts for the shading of S which was observed to be much weaker stigma than that coming from other stigmatizers.

Behavioral Manifestations

The behavioral manifestations were either overt acts directed at the hansenites or rituals and practices of the group towards hansenites. Acts such as covering the nose with a hand in the presence of hansenites, teasing, laughing or jeering at them were practiced usually by children or young adults who belonged mostly to the X group in the community. More serious acts of ostracism or isolation which signified strong stigma were also gleaned from the data.

The medical staff at the Central Mindanao Sanitarium related how when they first moved to Pasobolong, they had to go out to the nearby community on an information drive to dispel the fears of the residents. They received numerous protests against the establishment of the sanitarium in that location. The children of the hansenites attending the community's school were even stoned by other school children.

Serious HD cases such as those with ulcers, clawed hands and other deformities were severely ostracized. The Jolo Sanitarium's social worker stated that these hansenites were treated like outlaws. It was not unusual that they were not allowed on public transportation. This was one reason why their relatives were sent to pick up their medication from the skin clinic.

The isolation of hansenites by the Tausug takes place at an institutional level and at the community level. The Sulu Sanitarium located in Jolo and the Mindanao Central Sanitarium located in Pasobolong, Zamboanga took in severe cases of HD and served as skin clinics for out-patients (5). The fact that the Mindanao Central Sanitarium was transferred from its original beautiful and scenic site by the sea to a location further out of town to make way for a tourist resort and golf course, reflected the attitude of society, in this case the government, towards hansenites (6).

At the community level, isolation of hansenites was either a group or an individual act. Communities of hansenites and their families have grown outside both hospitals in Jolo and Zamboanga. The hansenites in these communities were patients who had been discharged from these hospitals and those who were not eligible for admission to them. Due to ostracism, these hansenites preferred to live in these communities where they could identify with others and avoid stigmatization. It was often the case that their immediate families came to live with them. The following excerpts illustrate the views of the S and X informants respectively.

> If they are not patients like me, I won't mix (socialize) with them.

> God forbid, even it there is a relationship (between us), I won't want to live with them. I will truly (definitely) send them away (to a far place). May God send it (HD) far away.

The last example shows strong stigmatization. The informant was willing to ignore strong clannish ties with respect to hansenites. He emphasizes his strong negative feelings by calling on God at both the beginning and end of his statement. Another X informant said:

> Those who live with them will no longer eat where those having leprosy do. It seems that one having leprosy bathed in the water (well) in our place (community), people don't go to get (collect) water anymore because they know already (about it).

In the first sentence the informant speculated on what would happen in the household of a hansenite, giving his opinion on how he would have probably acted. He then went on to relate what actually happened in his community. The verb form of the Tausug word for leprosy is used and indicates the progressive nature of the HD. The particle "already" also indicates progression, from knowing about the hansenite to the resulting act of isolating him.

Several customs which were practiced by the community promoted the isolation of hansenites. One of these was the building of a separate house for the hansenite. This was usually located within the yard of the main house.

> The only one close to him was his mother. His mother is the only that takes him his food in a small house ... which was made for him near the fence ... there she takes him his food.

> He doesn't mix with others (socialize) anymore. People don't speak to him, for (its) truly contagious. Meanwhile, a house was built for him far away. We who lived nearby (neighbors) avoided eating chicken, eggs, water (bathing).

An informant used his religion to justify his isolation of hansenites.

> According to Islamic principles, we should avoid things which would harm ourselves.

Some members of the community isolated hansenites by simply avoiding them and the places they frequent.

> He should really stay by himself in a house or on an island.

> We can no longer go (associate) with each other, because he truly (has it), even if we are close friends. I am ashamed (embarrassed) to go with him, and he too (is embarrassed) to face me.

The hansenites feared unemployment. This fear contributed to building up stigma. The prospect of an unproductive future caused depression and at times motivated attempts to keep their sickness a secret. An informant expressed her belief that HD was not contagious but then contradicted herself by saying that she would not hire a hansenite.

> If you don't have the same blood as they do, even what you do, you won't (get it)... It's hard to have them here (hire them) with a child (in the house). I will not get (hire) one if I know he is sick.

Psychological/Mental Manifestations

Linguistic evidence of the Tausug's stigmatization of HD was easy to discover. The terms they used to refer to the disease indicated psychological or mental manifestations of stigma. The term for HD in Tausug is ***ipul***, but this was studiously avoided due to the fear that the mention of the word could cause contamination. The strong aversion to the effect of HD on appearance or the squeamishness triggered by the term resulted in several substitutes for the term.

One substitute was the term leproso from the Spanish lepra, or English "leper". The terms "leprosy" and "leper" may be highly stigmatized in English-speaking communities but these and leproso were used by the Tausug precisely to avoid the indigenous, more emotional, ***ipul***. Because these are foreign and foreign sounding they are free of negative connotations. Borrowed terms neutralize the negative effect which the indigenous term may connote.

Other terms were used, most of which indicate strong stigma. The least negative of these terms is derived from the root "sickness". This term seemed merely to state "having the sickness" but the fact that "the sickness" was invariably understood to be HD said a lot. The term was also considered derogatory. Four other terms use the noun "sickness" along with a descriptive word: "sickness (that) melts/disintegrates/rots/ or wears down", "bad sickness", "sickness which cannot be named", and "different/strange sickness". All four are terms indicative of the attitude towards HD. The first one showed the fear of physical deformity. The next two connoted fear of something which was evil or unmentionable. The last one hinted of mystery; it connoted something that was beyond specific labeling.

Four more words added to the overall picture of the Tausugs' attitude towards HD. These were "condemned, "kung fu", "lumpy (like mung beans)", and "crooked". The first term obviously indicated the helpless and hopeless perception of HD. The second one revealed the derision that accompanied stigmatization. The term referred to the claw-hand of the deformed hansenite which was likened to a hand position of the Kung Fu combatant. This term was usually used for teasing or when referring in a light vein to a hansenite. The term for "lumpy described the lumps on the face which were usually associated with HD. The repetition of the word mungo, a small bean, connoted a number of them. Like "kung fu", this term was used in derision. The last term "crooked" described the deformity brought on by the disease, and reveals the perception that HD is crippling and disabling.

Self-stigma

As part of the community the hansenite possessed the same attitudes towards HD as the rest of the community. The hansenite subjected himself to some degree of self-stigma. The stigma often diminished after the hansenite realized or accepted that he had HD (see Fig.2) and learned to cope with it. Initially the hansenite subjected himself to some degree of self-isolation. Some hansenites manifested this overtly by keeping to themselves, hiding or avoiding strangers. This was also manifested covertly in the language the hansenites used in speaking about themselves.

There were two linguistic strategies used by the informants which contained self-stigma. The first was avoiding the name of the disease and using substitutes. "This sickness", "the sickness",

"that sickness", "different sickness" were the expressions used in lieu of the word for HD. The second strategy was the substitution of the first person singular pronoun "I" and "I (enclitic form)" with other pronouns, usually the plural forms "you and I (exclusive)" or "we", by hansenites when talking about their sickness. This was to deflect attention away from the self (singular) by seeming to include others (plural).

> Our sickness is like the one in Pasabolong.

This did not mean that the hansenites did not reveal their self-stigma overtly or in a direct manner.

> Nothing really, only we who are sick we are ashamed already of our bodies, even ourselves, we cannot go near (others) we are ashamed already.

> In the beginning my sickness wasn't noticeable, I socialized with others, now I'm ashamed.

> When we were (already) sick our bodies were no longer the same as all other people. We are ashamed to face others.

> I'm ashamed already to show myself because it's like ... I'm ashamed already to show myself because my body has the sickness.

In the last example the discontinued sentence showed the hesitancy of the informant, while the repeated sentence showed his anxiety over his sickness, which he said was in his body. He could have simply said that he was sick.

> It's restricting. I like to attend services (go to the mosque). Eh, I can't attend services anymore.

The short sentences show this hansenite's preoccupation with his plight, not being able to go to the mosque to pray. He repeats this for emphasis.

Another hansenite said:

> If they are not patients like me, I won't sit around with them.

The following account of self-stigma is from the point of view of a friend who did not wish to stigmatize but could not overcome the fear of contamination. Although the informant attempted to overcome stigma in the name of friendship, her hansenite friend perpetuated the stigma herself.

> Oh, I don't know. We don't see each other anymore ... because she'd ashamed of herself. Since we're close friends, I visit her sometimes but she hides. I know (she was there) because I can always see her slippers at the door. They mock her but without her knowledge.

Even if she is my friend I really feel revolted and fear contamination with her sickness. When she was (still) able to be my friend, she was so clean.

The Tausug shed their shoes before entering a house. The reference to the slippers at the door in the above excerpt was a way of saying that the hansenite could not hide the truth. The excerpt illustrates self-stigma and external stigmatization by indicating that the hansenite was teased and talked about "without her knowledge". The last sentence expressed the concept of HD as a "dirty disease".

The following excerpts describe self-stigma as observed by informants from the K (kin) and A (associate) groups.

> He just sits around the house that way. That's it, he just stays at home. He doesn't have work anymore because he can't get any kind of work. Whatever work, people will not what's this, not even minding chickens, if they find out they will not buy (from him) because they are careful that they (the chickens) may have eaten that, yes, the excreta, which they say has those (germs).
>
> Eh, he was ashamed. He did not go out also because people would what's this, also like that, like they were revolted by him. Eh, he was the one who wanted (to act that way/stay home).
>
> My friend Tagaran, I think she's from Alu, she often covers her head (and face) with a towel, it's like what you would say... damaged (already), and even her little fingers. The thing on her body at times, she wears long clothes, she lengthens them like that to hide that (thing).

The language in this last example illustrates the self-stigma of a hansenite and stigmatization from a non-hansenite. The informant clearly revealed her attitude in the use of the filler "that thing", by avoiding the mention of the symptoms "the thing on her body", and by avoiding the term for HD and substituting "that (thing)". The description of the hansenite's manner of dress illustrates self-stigma.

The social worker at the sanitarium in Jolo related how wary the hansenites were with strangers who came to visit. She recalled their behavior during the periodic socials which were held by the staff. According to her, although the hansenites rarely expressed their shyness verbally when exposing themselves to strangers, they hesitated to mingle with the visitors, first waiting to see if the guests showed any signs of aversion. When the patients suspected this they left the room. At times some informants felt that the guests might not know of their ailment. They would say "M'am/Sir don't get too close. I am a hansenite, in case you don't know." When a guest would offer to shake hands, the patients were heard to say: "M'am/Sir don't hold me because I have not taken my medicine yet."

THE IMPACT OF STIGMATIZATION

The Tausug's perceptions of HD and the causes and manifestations of stigmatization have been discussed. A logical sequence to this is to examine the effects of stigma on the hansenites and the rest of the community. The data show that the negative impact of stigma on hansenites and non-hansenites resulted in the breakdown of social norms highly cherished by the Tausug. Relationships within the extended family suffered to the extent that often the patients could only interact with members of their immediate family. The relationships within the peer group were also strained although efforts were made to avoid shaming the sick member of the group. Confrontational situations were avoided as much as possible. This often resulted in the isolation of the stigmatized. The hansenites showed their bewildered and emotional state by constantly questioning "Why do I have the disease? What is to become of me?"

Life Event Stresses

The results of the psychological testing shed light on the effects of stigma. The purpose of the psychological testing was to identify the stresses which underscored the impact of stigma. The tests showed that hansenites were most distressed by life events related to HD. They ranked these in the first 10 of a list of negative events which they considered most stressful.

The male respondents ranked "Seeing my spouse get stabbed by an enemy" as 1 with a 98 value, but the succeeding ranks 2 to 8, were all stressful events suffered as a consequence of HD. The female respondents on the other hand ranked the negative events related to HD 1 to 9 with "Death of my grandmother" intervening as rank 8. These stressful negative events are listed by rank and value in Table 3.

Table 3

Negative Life Events

	Male		Female	
	Rank	Value	Rank	Value
My shame and sorrow about the disease	2	96	4	85
Getting sick with leprosy	3	95	5	84
When my sickness (leprosy) gets worse	4	90	9	75
People avoid me because of my illness	5	86	2	87
Hearing negative remarks about my illness	6	85	1	89
People tease me about my illness	7	84	3	85
Borrowing alot of money because of my illness	8	83	6	82
Inability to earn a living because of my illness	10	80	7	76
When my back gets swollen because of my illness	16	66	11	72

The females generally had lower estimates for negative events. This could mean that females were more conservative in quantifying their experiences than male respondents. However, the female respondents gave higher values to the events related to the need for affiliation, demonstrating that they value this more than the men. Another interpretation could be that the women were able to handle the stresses that came with HD better than the men and therefore did not perceive these stresses as negatively as the men did.

The role of the male, as breadwinner and protector of the family, places him in a more stressful situation. This was evident in the rating for "Inability to earn a living" (M=80, F=76), and "Seeing my spouse get stabbed by the enemy" (M=98, F=49). For most of the women the focus of stress was on the interruption of social life and depression resulting from isolation. This indicates the sharp contrast between their social interaction before and after their diagnosis as hansenites.

Of the positive life events (Table 4) identified by the hansenite respondents, only one event, "When I did not have the disease", was related to HD. The male respondents rated this number 3 and gave it a value of 88, while the females rated it number 8 with a value of 71. Both groups rated affiliative events such as "Seeing my children grow up" or "Graduating from college" higher.

Table 4

Positive Life Events

	Male		Female	
	Rank	Value	Rank	Value
Seeing my children grow up	1	94	1	91
Graduating from college	2	89	2	82
When I did not have the disease	3	88	8	71
Relationship with God	8	81	4	80
When God showers me with blessings	9	79	7	72
Succeeding in business	7	83	18	52
Whenever I have money	6	86	11	69
Being with my children	11	76	9	70
Going abroad	5	87	15	63
Having sex with my spouse	10	79	17	55

Emotional Effects

Other emotional effects of stigma were hopelessness, anxiety, melancholia, wistfulness, bitterness, resentment and a determination to get well. One of the most common was the feeling of hopelessness. This was particularly expressed in relation to attaining goals.

> If I didn't become sick like that, I would have finished my course. My ambition was to become a teacher. If I didn't become sick I think my future would be very very good.

Eh, if I didn't have leprosy, I think I could work, go to school.

If my sickness would leave ... I could work well, I could join/socialize with my friends (peer group) again.

When a person is sick like you (plural) he is useless. They say that a person who is sick has no more value.

Notice the use of the second person plural by the hansenite in lieu of the first person. As discussed earlier this is a form of stigma.

Those of my classmates who finished school, (one) is now even a principle in Bongao. My parents really wanted me to go to school. The reason I couldn't finish was because I was very much ashamed (of my sickness).

In the case of other patients, the effect of stigma amounted to despair. In a conversation which centered around a hansenite's social relations with friends he suddenly said:

Death will solve all problems.

For some hansenites a jail sentence was preferred because at least it had a time limit.

I prefer to be jailed. In San Ramon (penal colony) there is still hope to be freed. This is because there is a sentence. But I believe this sickness is forever. The future of this is just to wait for death. This has no future; this sickness here stuck in my body. (I) can't walk around freely; can't work well because we(you and I) have this defect already.

Surprisingly, one informant even expressed preference for something that HD could cause, amputation.

If I were to choose, it would be better to have one of my feet cut off, rather than to be sick like this. Because people consider us dirty. One more thing, we can no longer join a group of friends and walk among a crowd of people. They abhor us.

Understandably, the hansenites suffered melancholia. This was usually expressed along with the lament over the loss of friends.

I have no more friends since I have had this sickness. My only friends are my relatives.

My problem is that I am alone now. My condition is sad. All is sad.

Another common lament was not being able to go to the mosque.

Since I became sick like this, I no longer go to the mosque because I am ashamed (to face) my friends and others.

Often, along with a deep sadness was a desire for what the hansenites perceived as beyond their reach.

> My heart is sad. I want to become clean like I was before. Even if I am now old, I want to be without sickness, unusual/unmentionable sickness.
>
> My ambition/desire is to become like everyone else, (that is) also my children.

According to the medical staff at the skin clinic, some patients were not satisfied by the treatment prescribed by the doctors. They impatiently asked questions such as "Why are you prescribing only this?", "Is this all you are going to do?", "Aren't you giving us other medicines?". Most often the reaction to the diagnosis was an expression of disbelief and or tears.

Bitterness and depression were effects caused by the belief that HD was not only a punishment for a transgression but that it was almost impossible to cure. Despite this attitude the Tausug still called upon God for help.

> So all I could do was ask help from God. I said/asked myself "Why were you punished?" I became like this for no reason. What I desire very much is to get well.
>
> Our family lived at a distance. Every time I went to the well the people (there) would whisper, "Don't what's this (go there), that sickness is contagious". It affected me, deep in my heart I was very sad. I did not tell my father because I feared that my father would get his knife to hack them. I just let it go. I just cried. "Never mind", I said to myself, "If this sickness was truly given to me by God, then may you (plural) become like me".

The language of the informant in the last example depicts the progress of her emotions from unhappiness at being ostracized to suppressing her desperation by simply resorting to tears, then trying to cope by venting her resentment in a curse.

In this example the hansenite uses two words for "whisper". One of the words incorporates the Tausug word for rumor. The use of both terms emphasizes the act itself, and also indicates that she considered the whispers as rumors and idle talk. Unlike other informants, she did not simply say "God made me sick". She chose to say "... the sickness was given to me by God", implying that she had to bear what was given specifically to her by God. The strategy she had chosen to cope with stigma was expressed by her vindictive curse.

Often the effect of stigmatization on the sick was one of deep resentment. Some considered being labeled as a hansenite their main problem in life.

The single positive effect of stigmatization was a determination to get well. Patients who were effected in this manner voluntarily went for medication and followed doctor's orders.

> I thought that because my friends were no longer the same/did not relate to me as before, I believed, I really thought about it, I should have myself treated.

> All I know is so that they can't call me a leper, I should have this wound on my foot, all of it, really cured.
>
> I do want to what's this, to get cured. I want to go to the doctor already because I want my body to get well.

In the last example the hansenite kept repeating "I want" emphasizing a great desire to go for medication in order to get well.

The following example shows the despair one informant suffered before deciding to take medication.

> When I realized that I was sick, I did not know for sure that it was leprosy. I went to the doctor. (He said) to me, "Your sickness is leprosy. You should take medicine". When I was told this by the doctor, I was very sad. I almost ... I told myself, "I better die". But I could not afford/have courage to (kill myself). So I took medicine. I also thank God that my sickness is now better".

In the next example an acquaintance of a hansenite expressed his willingness to renew relations with a hansenite on the condition that he got cured, for then fear of contagion would no longer be present.

> If, for example, he gets cured in the Skin Clinic of the Sulu Sanitarium, then I will no longer be afraid of getting infected because I think if the doctors are able to cure that sickness it should no longer be contagious.

The following case shows a positive effect of stigma. A barter trader, urged by friends and relatives, went for consultation at the out-patient clinic of the Sulu Sanitarium which treats skin diseases including HD. Confronted with the fact that he had HD and would inevitably be stigmatized, he did not return for the scheduled visits to the clinic for fear that his sickness would become known to others. The social worker and a nurse went to the barter trade market to look him up. He admitted that he was being ostracized by his fellow traders who suspected that he had HD. After talking to the social worker he went to the clinic to request a certificate stating that he had an allergy, not HD. This could not be done but the doctor and nurse reassured him that he would be able to go on conducting his business as long as he took his medication. They also convinced him that the spots on his skin would disappear. He had not been taking his medicine because he had refused to accept the fact that he had HD. When he realized that his associates would continue to shun him as long as his symptoms persisted, he accepted that he had HD, registered as an out-patient and went for regular check-ups and medication.

A similar case was that of a wealthy man who kept his sickness a secret by going all the way to Manila for medication. Eventually he sought help from the local clinic when he ran out of medicine before his next trip to Manila. Since there was a marked improvement in his condition, he began going regularly to the local clinic and as a precaution sent his children for regular check-ups.

STIGMA MANAGEMENT

Different coping strategies come into play when stigma has to be confronted. These are best understood from the point of view of the sick and of those who deal with them.

Acceptance

One way of coping is by accepting the consequences of stigmatization and trying to live as normally as possible. This is illustrated in the following excerpt by a hansenite who chose to ignore the heckling and teasing at school and to continue to attend school.

> Even in school there are those who already think badly of me, but I no longer bother about them. I just let it go.

Another informant expressed his intention to go on working while he can.

> What I intend to do is work while I can still work.

An informant reported that his neighbor, a hansenite, did not seem to be affected by stigma.

> I think he was not (affected) because he used to gallivant around town.
> Yes, he usually even goes to market.

In some cases, patients were resigned to both their condition and the attitude of the community towards them. This was expressed in terms of being patient and accepting what may come. They learnt to live with stigma, evading and avoiding confrontations with possible stigmatizers.

> If I weren't sick like this, I desire (deep in my heart) to go to school so that I can be employed. Up to the present, I haven't gone to school because I am sick. I'll just wait for whatever work comes (my way). I just have to be patient.

> Even if we (I) get angry, it is no use if it's there already.

Converging in Communities

The hansenites who manifested self-stigma by self-isolation coped with their predicament by converging in communities. In these communities, just outside the walls of the sanitarium, they were able to avoid stigmatization.

> Ah, the people here, we are like relatives. All who are here, we are like brothers and sisters.

The strategy of starting both his sentences with reference to "all" and "the people" gave emphasis to what he wanted to communicate, a prevailing community atmosphere. One that was just as effective as elsewhere since its members were like relatives, like brother and sister, a clan.

Other hansenites resorted to coping by being self-sufficient in self-isolation.

> I don't work for people/I am not employed. I like to be by myself. I am ashamed (of myself) to do work for other people. I like to earn my livelihood on my own, by myself. I'll survive in the fields even if I don't work in the employment of others.

Notice the repeated use of the first person pronoun "I" and "by myself" to stress his self-isolation.

Denial

Another form of coping was to deny knowledge of HD.

> I don't know (about it).

> Me, I am not sick. I'm normal.

Some patients explained their presence in the skin clinic as seeking treatment as a precaution against catching the disease. The records showed however that they were actually active cases.

> I don't think I am sick with what they call leprosy. I only do this/come here as a precaution.

The stepmother of a patient flatly denied that anyone in their family had HD.

> None of us have the sickness. If there were, I should..., if there were I should avoid them.

Notice the repeated phrases which showed the informant's uneasiness at expressing what was contrary to the fact.

The skin clinics' staff reported of patients who pleaded that their sickness be recorded as cases of allergy. When several patients identified by these clinics as positive for HD were interviewed they claimed their sickness was an allergy. The social worker at the Sulu Sanitarium also related that some patients had asked her to record their sickness as an allergy. In one case an informant claimed no knowledge whatsoever of the disease.

> I don't know any sickness like that.

As the conversation progressed however, she belied her statement by referring to a hansenite of her acquaintance.

> It is like the sickness of Ikong.

Another informant said:

> "What happened (to you)?" What's that?", they asked. "Isn't that the work of man?" Eh, I said, "I don't know." And yet I have already been using the tablets/pills. I simply said/answered, "I don't know."

The informant employed direct quotes to highlight how he was taunted. His feigning ignorance, which he repeated, showed how he coped. Despite this, he revealed how he still suffered from stress by his perplexed and resentful statement that he was taking medicine.

Often, hansenites expressed skepticism about the nature of their aliment.

> Its leprosy they say.

> They say I'm a leper.

The wife of a hansenite claimed:

> I don't know anything about the sickness of my husband/I don't know what my husband's sickness is.

The curt answer in the last example revealed the informant's unwillingness to talk about HD. A daughter-in-law claimed she did not know what her mother-in-law's sickness was called. When HD was suggested she answered: Maybe.

Fatalism

Influenced by their religion, fatalism was often an attitude the Tausug capitalized on in order to cope with their predicament.

> I have nothing to blame (for this), in reality it's God who made me sick like this.

> What can we do, never mind. Nobody (would) wants this to descend (on himself). This is like ***sukut.***

Sukut is a ritual offering to the spirits. The informant considered his sickness as something demanded by the supernatural, therefore it was his fate. Note the choice of "to descend", which could have been expressed by a word meaning to become sick or to have HD.

Some hansenite informants even expressed preference for HD over other sickness believing it to be God sent.

> Whatever is given to you by God, (you must) suffer it.

> We can't refuse/reject it (HD), because there is one who decides (things) for us.

If he says, you'll get sick or you'll die, we can't refuse. I will not die yet (until God wills it).

Belief in the Power of Prayer

Closely related to fatalism is the belief in the power of prayer. For those who believed HD was sent by God or that it was a curse, a supernatural cure such as prayer was credible. The dominant religion is Islam. Prayer is part of the fabric of daily life. Turning to prayer and with great faith in this as a solution, the sick and their families were able to cope with their problems.

The cure for it is forgiveness and prayers, for the one cursed and for the one who cursed (him).

Secrecy

The following cases illustrate coping by secrecy.

One of the cases treated in the Zamboanga skin clinic was a transient, an Ilocano who came all the way from Northern Luzon. When her condition improved after a year of drug therapy she went back to her home town. She returned to Zamboanga for treatment when her symptoms reappeared. In this way she hid her condition from her townmates. Only her closest relatives knew she had HD.

The Muslim patients at this clinic were brought there by an "agent". This man, who went by the alias Boy Lali, would speak for them and accompany them each time they came for medication. When attempts were made to locate him at his given address in Riohondo, the Muslin ghetto in Zamboanga, nobody admitted knowing him. All the patients whom he regularly brought in for medication and periodic treatment had registered under false names and addresses. Some of these addresses were located but the people who lived there denied knowing a hansenite or having heard any of the names which were registered at the skin clinic. They also denied knowing a Boy Lali.

The medical staff at the skin clinic of the Jolo Sanitarium reported that the patients who live near the Provincial Hospital which has the facilities to treat them, preferred to go to the skin clinic which was further away in order to avoid detection from their neighbors. Since the skin clinic also treats other skin diseases, it was easier for them to claim they had a skin disease other than HD.

At times the hansenites resented this strategy of secrecy but had to go along with it.

We were not sent to school, we were hidden by our elders. That's why we are stupid.

Belligerence

The relatives of the hansenites usually coped with stigmatization by resorting to fatalism, acceptance or secrecy. But quite a number faced the problem with belligerence and threats of violence. The mother of a hansenite claimed that no one dare mock her daughter.

None (mock), because they are afraid of my children (boys). If they mocked, they will have a big fight with my boys.

A hansenite's father expressed his resentment against those who stigmatized his child by wishing that they should get HD. He enumerated them thus:

Those who are squeamish, those who mock, those who on seeing serious cases (of HD) laugh, they don't have compassion when they see those who are sick (with HD).

It was often the case that the neighbors preferred to avoid trouble, hence they were careful with what they said in case they angered the hansenite's family.

MEDICAL STAFF

To complete the picture of stigmatization among the Tausug it was important to study the attitude of the medical/health personnel (H) in the community who were involved in the treatment and rehabilitation of the hansenites. Although a number of the personnel were not Tausug they could speak or at least understand Tausug.

It was also critical to establish whether the health staff contributed to the perpetuation of stigma and if so, in what ways. This information was obtained by conversing with the medical staff of the Mindanao Central Sanitarium, the Sulu Sanitarium, the Sulu Provincial Hospital and with the Barangay Health Worker of Danag, Patikul, and Jolo.

Because of the strong stigmatization in the areas studied it took a knowledgeable and dedicated staff to work with HD patients. Most of the H informants expressed satisfaction with their work and said they had no desire to change work or be transferred to another type of work.

Almost all of the H informants got their training on the job. They had no specialized training on HD or how to deal with hansenites, and had practically no knowledge of the epidemiology of the disease when they started. Some of them had subsequently taken seminars on HD. Despite this they developed into efficient health providers with a reasonably positive outlook towards HD and hansenites.

Most of the health informants felt they had a mission to fulfill. This was to prevent the disease from progressing in their patients and to rehabilitate the physically deformed. They felt it was part of their duty to give hope to their patients.

Despite the sincere, conscious and overt efforts of the medical/health staff to help the patients and to avert stigma, some problems persisted. Having been exposed to the community or possessing the indigenous cultural norms, the H informants still manifested traces of stigma. This was revealed in their speech.

The Tausug health informants avoided mentioning the name of HD in their language. They would rather say "It's like that" or "It's that sickness". These informants admitted that they were initially afraid and revolted by what they had to work with.

> When you (first) see his deformity you are afraid because you still don't know the real cause. But when you get to know what it is, (your fear is) no more.

In their place of work, members of the staff were at ease and seemed free of stigmatization, but once outside the sanitarium or clinic, they were careful in referring to their work. Invariably when asked if they would not mind having hansenites as household help, their answers were not categorically "yes" or "no". Their answers were usually a strategy of avoidance. For example, quite a few gave an indirect response to this query, such as saying that their patients often helped out with office and clinic chores.

The staff members referred to those patients who no longer showed symptoms of HD as "clean", implying that those with HD were "dirty". This was in consonance with the Tausug's perception of the disease as dirty.

Their close association with hansenities exposed these personnel to stigmatization. It usually came in the form of light teasing such as "You have it, don't you?" In fact, most members of the community avoided the sanitarium for fear that if they were seen coming out of it they would be suspect.

The doctors at the skin clinics and sanitaria complained that patients came to them only after being treated for other skin ailments such as allergies by doctors who were not able to diagnose the disease correctly. Usually these doctors had not seen a case of HD and could not recognize one when they did. At times, if these doctors suspected their patients were hansenites they postponed or avoided telling them the truth because of the strong stigma their patients would have to suffer.

Dr. Florentina Castillo, Head Administrator of the Sulu Sanitarium relates an interesting case where her neighbor, a military man, was diagnosed by her to be a hansenite. He refused to believe the diagnosis and went to consult the doctors at the military hospital. There he was told that the doctor who had diagnosed his sickness as HD was stupid. They diagnosed his case as an allergy and treated him for this. After a time he went into reaction and was treated once more for allergy. When he was in severe reaction and was bloated, he was airlifted to Manila. His wife sought out Dr. Castillo to tell her that her husband did not, after all, have leprosy. The doctors in Manila had diagnosed his case as Hansen's Disease. The wife was more amenable to this diagnosis.

CONCLUSIONS AND RECOMMENDATIONS

The purpose of this study was to describe and analyze stigmatization in relation to Hansen's Disease among the Tausug and to arrive at a body of knowledge which could be used in local and national health education, medical staff training and disease control programmes. By applying a psycholinguistic, historical and psychological approach to the problems of HD stigma among the Tausug, the study documented the processes of stigmatization, its causes and manifestations as well as the impact and management of stigma for hansenites, non-hansenites in the community and medical staff.

The study revealed that stigmatization was the consequence of the reactions and attitudes of the community to HD and to those who are sick. The factors responsible for this attitude its manifestations and its effects form the Tausug's ideology of stigma. This ideology can seriously mitigate against successful treatment of HD unless recognized and included in health and education programmes.

On the premise that the ideology of stigma is key to communicating pertinent information effectively to targeted groups in the community, a knowledge of the ideology of stigma will be of great assistance in developing educational material and health programmes that ensure a more effective means of controlling the disease. Educational material based on this knowledge should dispel the fears and negate the misleading perceptions and beliefs which have prevailed and supported the group's attitude towards and treatment of HD. At the same time, positive factors in the belief system of the Tausug can be utilized in giving credibility and relevance to the material. These positive factors, which the Tausug will recognize, understand and relate to, can be used as starting points in organizing educational materials.

What follows then are some suggestions and recommendations for health and education programmes derived from this study on stigmatization of HD among the Tausug. Although further recommendations and suggestions could also be advanced from the study, these recommendations are primary.

Concept of *Kagaw* and the Perception of HD

The concept of ***kagaw*** could be capitalized on in health programs since it reflects, in some way, the scientific concept of the micro-organism and should not be dismissed as mere superstition or ignorance. Educational material on causes and transmission could use this term and build on the idea that the organism does cause HD.

Among the Tausug, ***kagaw*** could also be used to dispel the perception that HD was brought on by supernatural causes such as fate, spirits and curses. Since it is living organisms that cause HD they can be killed. Further, educational material can demonstrate through this concept that HD is not a highly contagious disease by disproving the strength of the ***kagaw*** and countering the belief that it is practically indestructible or that it can crawl rapidly from one host to another. It can be emphasized that the strength of the ***kagaw*** could be reduced by faithfully taking the prescribed medicine.

The perception that HD is a "dirty" disease was partly responsible for the revulsion that caused stigma. Educational material should dispel this by stressing that the symptoms that brought on this perception of being dirty only appeared when the disease is neglected.

Perceptions of HD Transmission

The Tausug's perceptions on HD transmission all relate to the actual means of transmission, prolonged contact. The perceptions that HD is transmitted by poor health habits, neglect of skin ruptures, or because of weak blood all reduce to a poor state of health. Undoubtedly, anyone in a poor state of health is susceptible to disease. Transmission by heredity and by contact with hansenites, the other Tausug perceptions of transmission, are closely related since contact is sure to happen when a family member has the disease. Educational material using the Tausug's perceptions of transmission would be credible and more easily accepted.

Fear of HD and Stigmatization

The fear of HD and the fear of stigmatization should be addressed when fashioning educational material for HD control. For example, the strong fear of physical deformity which is perceived to be inevitable with HD should be given special attention. This fear could be dispelled by highlighting the advantages of early detection and stressing that deformity comes with the neglect or delayed treatment of HD which are often due to the denial of the disease or to ignorance.

The study also suggested that hansenites, unlike non-hansenites, did not fear HD itself. Having the disease without any sudden crippling deformity or disfigurement did not make them terrified by the anticipation of what might happen. The slow progress of the disease conditioned the hansenite into adjusting to disablement. Several hansenites, in fact, expressed a preference for HD over diseases like cancer and tuberculosis. What the hansenites actually suffered was fear of stigmatization which often gave rise to self-stigma. In some cases self-stigma even preceded stigmatization from others.

The patients fear of HD and stigmatization was sometimes interpreted as hardheadedness by medical/health staff when they were unsuccessful in delivering treatment to patients.

The research also revealed that fear of losing the ability to earn a living was a cause for fearing HD. Information to contradict this fear of economic displacement, which is greatly responsible for stigma should be given prominence in educational material and staff training programs. Strategies to dispel this fear should be geared towards convincing the target group that HD does not necessarily mean an unproductive life. The hansenite must be convinced that having the disease should not be synonymous with inactivity or uselessness. The educational material should emphasize that there is life after HD.

Acceptance and Coping

It is imperative that educational material on coping with stigmatization be fashioned in a positive and productive manner. Hansenites and their families tend to cope with stigmatization by secrecy and avoidance. The disadvantages of this manner of coping and the advantages of facing HD as early as possible should be emphasized. This does not mean coping by resigning oneself to stigmatization. Rather it means that any sign of the symptoms should alert one to seek medical help and after a positive diagnosis should spur one to pursue medications.

In addition, educational material should include accounts of the positive manner in which some of the informants of the study were able to cope. Again, this was done by the hansenites first accepting the fact that HD is curable then realizing the effectiveness of drug therapy and regular checks on the progress of their treatment.

The results of the psychological testing of life events suggest the necessity of developing intervention strategies which take into account ethnic and sex differences. Patients, medical workers, and the rest of the community must be appraised of the psychological factors attendant to understanding HD. The negative stressful events rated high by the respondents indicate that the problems related to these events have to be addressed in the educational material on causes, transmission, cure and on coping with stigma. The positive stressful events, on the other hand, give clues to the general aspirations of hansenites. Educational strategies which could inspire hansenites to attain their aspirations despite their sickness have to be found.

Medication Effectiveness and Use

A relevant simple presentation of the drugs needed for medication should be developed. The scientific and generic names of the drugs are strange, foreign sounding and therefore difficult for the Tausug to remember. The Tausug informants identified drugs by color and size rather than by name.

The Tausug also conceptualize time in chunks rather than in units (hours, days, weeks). Time is reckoned by relating events to the position of the sun, light of day, or in relation to seasons and predictable events. It was observed that instructions for drug intake in the usual Western manner were difficult for the Tausug to internalize. All of these items have to be considered when giving instructions for medication.

A careful explanation of possible reactions to the drugs must also be made. Often the patients concluded that such a reaction was a failure of the drug to cure and therefore felt that the drugs only aggravated their suffering. Many hansenites stopped medication due to this. In the educational material the language used to describe the reaction to drugs should utilize the words the Tausug use to describe their symptoms. This would facilitate their understanding of what they can expect after taking the drugs. Realizing the effectiveness of the drugs (through proper information) would help convince the hansenite that getting cured is the best way to overcome stigmatization.

Importance of Family Affiliation and Religious Culture

The study established that stigmatization is relative to the degree of kinship and social affiliation. The lesser the degree of kinship or social affiliation the greater the stigma. Within the family, which included the nuclear family and close relatives, isolation when practiced was not complete or strictly followed. Ordinarily a separate house was built for the hansenite within the premises of the home, but some families let the hansenites live among them. Interaction within the family was maintained with awareness, tolerance and care. If any aversion was felt towards the disease and the sick, members of the family were careful not to show it.

Strong family ties often lead to the overprotectiveness of the hansenite by the family. This needs to be addressed in the educational material. The family must be convinced that their help and support could mean the eventual cure of their relative. The study showed that in some cases relatives were often instrumental in convincing the hansenite or the suspected HD case to seek treatment. Some relatives even took on the responsibility of picking up the medication or accompanying the patient for periodic check-ups.

Strong stigmatization was practiced outside the family. This was tempered only by fear of reprisals from the relatives of the hansenites and by religious beliefs.

In developing or revising educational material for the control program the importance given to family relations and the highly religious culture of the Tausug should be considered. Emphasizing that God rewards charitable attitudes towards hansenites and punishes stigmatizing acts, would be easily understood and accepted by this highly religious people.

The psychological tests conducted in this study further affirmed the importance of affiliation and religion to the Tausug. The events which caused the greatest stress were tied to HD. Having the disease brought on personal and emotional problems beyond the simple biomedical diagnosis and treatment. The significance of family ties or membership in a clan and the religious beliefs and practices regarding HD should be considered and utilized in the development of the educational material in the area.

Language and Training

In addition to developing appropriate educational material for the community the study revealed the need for enhancing the knowledge of the medical/health staff on the stigmatization of HD. The Tausug's ideology of stigma, knowledge of their perceptions, psychological factors responsible for their attitudes, along with a history of HD and its control would be useful material for upgrading and orientation seminars for health providers and new recruits. Such knowledge should equip them with an understanding of the behavior of the patients.

It can not be emphasized enough that the educational materials should be entirely in the language of the targeted group: Tausug for the community and Tausug or Filipino for the service providers. No extra effort would then be required by the target group to handle the problem of language and all efforts can be spent on understanding and internalizing the content of the material. Given the large number of groups where HD is found in the Philippines it is

impractical to produce one set of educational material for each group. It is recommended that educational material should be prepared in at least five languages: Filipino, the national language; and the four regional lingua francas, Ilocano, Cebuano, Hiligaynon and Tausug. Filipino, which is quite similar to Tagalog, the other lingua franca, could be used in the Tagalog region.

FUTURE RESEARCH

A natural sequel to this research on stigma is a project to develop educational material based on the findings and recommendations of this study. This would include the production of posters, pamphlets, slides and primers to be used in training programmes for the community as well as for service providers. This project could become a model for similar endeavors for other ethnolinguistic groups.

The conclusions and recommendations of this report resulted from a study of the Tausug and are pertinent to this group. Nonetheless, the recommendations without the details specific to the Tausug could be applied to a national control programme if further similar research on HD and stigma could be conducted in other areas where HD is highly prevalent. A comparative analysis of the results of these studies should then be made to determine what specifically can be applied to the national control programme.

Finally, it would be interesting and useful to know the results of studies related to stigma on other stigmatized diseases.

NOTES

1. This research was funded by the UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases.

2. The Philippines, a multilingual country, has a complex linguistic situation. The more than a hundred languages plus the impetus of two highly prestigious foreign languages in the past, Spanish and English, contribute to this complexity. Ten of these Philippine languages are called major languages since they are spoken by large linguistic groups often consisting of over a million speakers. The rest are called minor languages sometimes spoken by a few thousand. Presently, a lingua franca or common language is spoken throughout the archipelago. This language is Filipino, the recognized national language. Besides this there are five languages which are considered regional lingua francas: Ilocano spoken all over Northern Luzon, Tagalog spoken in Central Luzon, Cebuano and Hiligaynon in the Vizayan Islands and in some areas in Mindanao, and Tausug in the Sulu Archipelago.

3. The study was originally planned to take twenty-four months to complete. Due to problems related to data gathering, such as travel difficulties and informants' accessibility, the completion of the research was delayed by several months. The collection of data lasted more than the estimated six months. Although most of the research team lived in the research sites the rest had to travel to the areas by plane or boats on very erratic schedules.

Another problem was informant accessibility. Some of them could only be interviewed in the evenings. Due to the unrest in the area it was often not advisable to go out after dark. The unrest in the area was due to the revival of traditional family feuds and the occasional raids of rebel troops.

4. The original Tausug is not included here but is available in a complete project report submitted to WHO.

5. Another skin clinic is located in the center of the city and is run by the City Health Office of Zamboanga.

6. One of the largest sanitaria, the Culion Leper Colony, was established on the remote island of Palawan.

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APPENDIX A

GUIDE TOPICS FOR RESEARCH ASSISTANTS

S - patients or those who have HD.

K - kin and relatives of S.

A - associates or friends of S.

K - those who do not know anyone who has HD.

S informants will be identified by means of clinical records and skin clinics, data of the Ministry of Health or of the Sanitarium in the locality. Individuals identified by members of the community as having HD whether or not this is verified may also be considered as S informants.

The data of S informants should carry the information on how he was identified.

SC - skin clinic records

MOH - data of Ministry of Health

San - community (K or A)

Participant observation

Besides collecting data through interviews; unobtrusive observation of the communities or surroundings where the informants live should be noted and included as a brief report with the data collected through the interviews.

A brief description of the house or household, such as the building material used for the house and what appliances were found should be noted. If the informant is interviewed outside the home this information should be obtained through the interview.

GENERAL INFORMATION FOR ALL (S,K,A,X,H)

Name

Address

Place of Birth

Languages spoken

What other places did he/she live in? How long?

Mother's origin and language

Father's origin and language

Address of parents

Highest educational attainment

Reminder: avoid asking direct questions.

PATIENT (S)

Name

Address

Place of Birth

Languages spoken

What other places did he/she live in? How long?

Mother's origin and language

Father's origin and language

Address of parents

Highest educational attainment

Find out what he considers his greatest problem. Lead up to this by asking about his job. Who his neighbors are. Who does he consider his best friend(s). Problems related to the above.

If the problem of his health does not come up ask him if he considers himself healthy. If not, why not, if he does, why

What troubles him most about his health?

- in relation to job, work companions.

- in relation to family, friends, strangers.

If HD hasn't been identified yet, inquire into the following: What does he call his sickness? What do others call his sickness? What do others call him? This information may be acquired at the same time inquiries about his health are asked.

Inquire about the history of HD in his family and community by finding out if he knows anyone else who has HD and gradually lead up to making him identify family, friends, neighbors, childhood playmates who had/have HD.

Ask him to relate an unpleasant experience related to his sickness, in childhood, school, on the job with friends/acquaintances, with health services/staff, with strangers. What does he do (has he done) to avoid such experiences?

Inquire about his religion. Lead him into talking about religious practices related to his sickness (or other similar diseases) he is aware of. Ask patient if his sickness prevents him from attending religious affairs. Is he barred from attending these? How?

Find out about his social activities. What are the traditional social gatherings in the community (community meetings, parties, barangay activities, others)? How often does he attend these? If not often, why? Does he frequent family gatherings? If not, why?

Inquire about his perceptions regarding undesirable effects of the disease. Ask patient if he would prefer a physical disability; e.g. large scar (peklat), limb (pilay) or filariasis/schistosomiasis/malaria/cancer to his disease (HD). Would he prefer his disease to blemishes on his character; e.g. dishonesty, imprisonment, alcoholism or mental disorders?

Find out about his perceptions regarding cause of the disease. Could the disease be caused by:

- retribution for something ancestors did
- retribution for something he did - personal misbehavior, wrong done to another.
- a curse (kulam)
- pasma
- unhealthy personal habits (hygiene)

Ask respondents what he knows about skin disease? What different skin diseases is he aware of?

Would he shake the hand or sit beside other persons? Would he allow a hansenite to cook his food or mind his children?

Inquire about the measures he has taken to remedy his sickness.

Who did he seek out to help him? A-herb doctor (manggagamot)? How often does he see the manggagamot? The-community, health worker or doctor, relatives, friends? Did he do any self-remedies? What were they?

How often does he visit the medical clinic? How effective has it been in helping him out? Ask patient to relate/describe procedure of treatment.

Ask informant to relate a usual day's activities from time of waking to sleep. Inquire about his friends. Who is his best friend? Does he/she have a peer group (barkada)?

What is his greatest ambition in life. What does he dislike the most?

Ask if he thinks he would have had a better life if he did not have HD. Who does he blame for his sickness?

How old was he when he discovered his sickness? How did he find out?

Does he like going to the doctor? How does he go to his doctor, and the hospital or clinic for medications? Does he think he is getting better/well? Let him relate what is done or what happens, step by step, when he goes for treatment.

RELATIVE/ASSOCIATE (K/A)

Find out what sicknesses he dreads most.

What are the different skin ailments he knows of, for example, tagulabay, an-an, galis, eczema, etc.. Ask him to describe each. Which of these would he dread having/be scared of.

If HD has not been mentioned yet ask him what he calls the sickness of his relative/friend (the one with HD, without mentioning the sickness). If he doesn't know, ask what he knows about "ipul" (or mongo-mongo, panyakit, kung-fu).

What does he feel about his relative's/friend's sickness. How often does he see him? When? Does he know of others in his family/clan who have the disease? Who? How are they related to him? Do they attend family gatherings? Are they sociable? Do they keep to themselves? Do others know he has relatives/friends who have HD?

Ask him to relate an incident in school/work where he had to face the problem of being identified with HD. Is his relative/friend teased? How? What names is he called? Is he himself ever teased? How?

Inquire whether they know of any folktale, story or song which mentions skin diseases or HD.

Has he offered to help out his relative/friend? How?

How does he think the disease is transmitted?

Would he mind if his relative/friend cooked his food, or minded his children? Is he apprehensive about contacting the disease from his relative/friend?

MEDICAL/HEALTH STAFF(H)

Find out what led up to their assignment to the job. Are they happy with their work? Would they rather be assigned to a different job? How long have they been on the job? How were they trained for it? What they consider the greatest problem of the job?

Inquire about their knowledge of HD by leading up to this through asking what they call HD in their language. If they are not Tausug, what is it in Tausug?

Do they know hansenites are teased? What are their duties in treating the patients? What precautions do they take to avoid contacting the disease?

What instructions related to HD do they give to patients?

What information about health care, causation, and transmission do they give them.

Find out if they know about government or private institutions/groups that are concerned with hansenites.

What do they consider their greatest problem(s) in dealing with hansenites? Other problems?

Ask them to relate the step-by-step procedure of treatment or consultation of patients.

Are they aware of any other terms used to describe HD or victims of HD? Are these used often? Where? In what situations?

Would they employ hansenites as house help?

How about inactive cases? Are they willing to socialize with them? Work with them in the same office?

APPENDIX B

CHECKLIST FOR PSYCHOLOGICAL TESTING

Table 1

Important Negative and Positive Life Events for Male Tausug Hansenites (N=15)

Rank	Negative Life Events	Value
1	Seeing my spouse get stabbed by an enemy	98
2	My shame worry and sorrow about my disease	96
3	Getting sick with leprosy	95
4	When my illness (leprosy) gets worse	90
5	People avoid me because of my illness	86
6	Hearing negative remarks about my illness	85
7	People tease me about my leprosy	84
8	Borrowing alot of money because of my illness	83
9	When I was in a bus accident	81
10	Inability to earn a living because of illness	80
11	Not being able to see my brother who died	72
12	Death of my mother	71
13	Having a stroke	70
14	Seeing my father get shot	69
15	When I quarrel with my spouse	67
16	When my back gets swollen because of my illness	66
17	Seeing my daughter unhappy	61
18	Seeing my husband get beaten up by enemies	57
19	Death of my parents	56
20	Getting married	48
21	When I nearly drowned	46
22	Death of my spouse	45

Rank	Positive Life Events	Value
1	Seeing my children grow up	94
2	Graduating from college	89
3	When I did not have this disease	88
4	Taking walks with girlfriends	87
5	Going abroad	87
6	Whenever I have money	86
7	Succeeding in business	83
8	Relationship with God	81
9	When God showers me with blessings	79
10	Having sex with my spouse	79
11	Being with my children	76
12	Being able to own a house	74
13	Being able to study	70
14	Seeing children finish college	67
15	High school days	65
16	When I courted my wife	64
17	Having a girlfriend	60
18	Having children	50
19	Receiving a reward in school	39

Table 2

Important Negative and Positive Life Events for Female Tausug Hansenites (N=9)

Rank	Negative Life Events	Value
1	Hearing negative remarks about my disease from other people	89
2	People avoid me because of my illness	87
3	People tease me about leprosy	85
4	My shame worry and sorrow about my disease	85
5	Getting sick with leprosy	84
6	Borrowing alot of money because of my illness	82
7	Inability to earn a living because of my illness	76
8	Death of my grandmother	76
9	Leprosy getting worse	75
10	Struggling day by day to have food	73
11	When my back gets swollen because of my disease	72
12	Getting married	69
13	Death of spouse	62
14	Seeing my father get shot	58
15	Being always financially hard up	55
16	Not being able to see my brother who died	54
17	Seeing spouse stabbed by enemy	49
18	When I quarrel with my husband	45
19	Seeing my husband get beaten up	45
20	Seeing my daughter unhappy	44
21	When I nearly drowned	39
22	Death of parents	30
23	Having a stroke	27

Rank	Positive Life Events	Value
1	Seeing my children grow up	91
2	Graduating from college	82
3	Going places with my husband	81
4	Relationship with God	80
5	Having children	80
6	When my husband courted me	75
7	When God showers me with blessings	72
8	When I did not have this disease	71
9	Being with my children	70
10	Getting married	69
11	Whenever I have money	69
12	Being able to study	66
13	Seeing children finish college	64
14	Being able to own a house	63
15	Going abroad	63
16	Taking walks with my boyfriend	60
17	Having sex with spouse	55
18	Succeeding in business	52
19	Having a girlfriend	51
20	High school days	41
21	Receiving an award	35